

The Physician's Role in PAD: Ethnographic Insights from Vermont

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Vermont's law: the "Patient Choice and Control at End of Life" Act (Act 39)

- Signed into law May 2013
- Requirements:
 - Terminal diagnosis
 - 2 voluntary oral requests, 15 days apart
 - Written request signed by two witnesses
 - Dx and prognosis confirmed by second doctor
 - Medication is self-administered
- Utilization: paperwork for 52 patients submitted as of 6/30/17



The Vermont Study on Aid-in-Dying

- 1) How do ordinary people understand, access, and contest AID once it is legally authorized?
- 2) How do healthcare providers and policy stakeholders accommodate or resist AID as a new end-of-life practice?
- 3) What are the ethical challenges for clinical communication and the patient-clinician relationship?



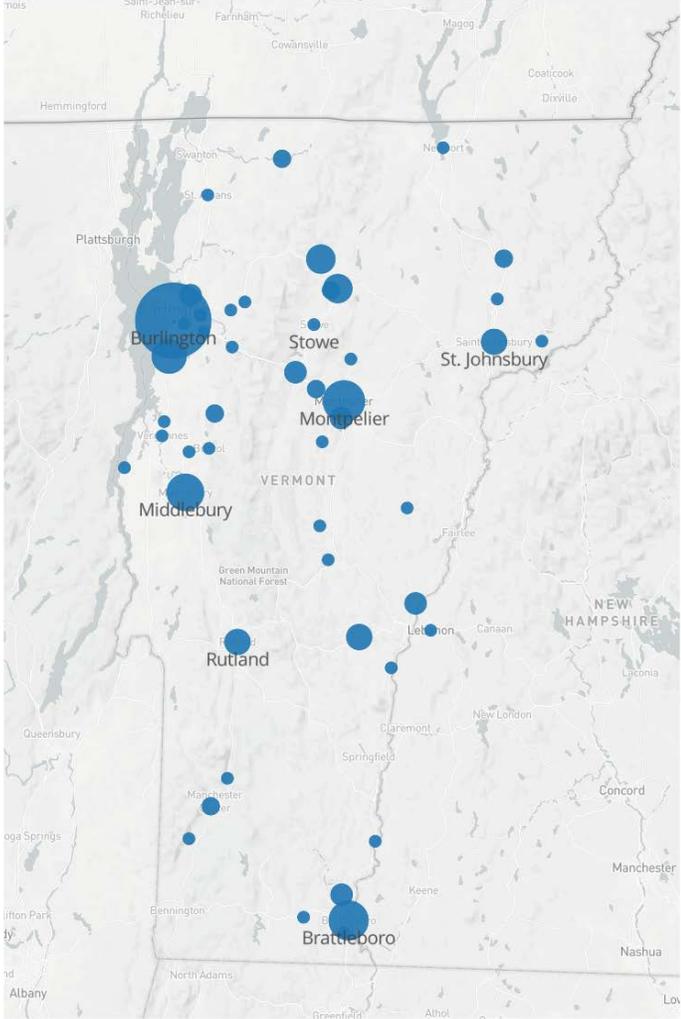
Methods

- 144 Semi-structured, in-depth qualitative interviews
 - Physicians (n=29)
 - Nurses, chaplains, and social workers (n=22)
 - Terminally ill patients (n=9)
 - Lay caregivers (n=34)
 - Policymakers/activists (n=37)
 - Other VT residents (n=13)
- range: 16-118 minutes, mean=57.5
- Participant observation: medical conferences, advocacy events, judicial hearings



Interview sample

Interview Locations



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Two key points

- 1) The physician's role is more than just writing an Rx.
- 2) The communication challenges are broader than responding to requests.



The physician's role

- Determining eligibility
 - Prognosis, competency, state residency
- Counseling and educating patients
- Finding a second physician
- Finding a pharmacy
- Figuring out what to prescribe
- Completing the bureaucratic paper work
- Planning for the death

- Conceptualization of practical and moral burden varies widely.



Lessons learned

“But that first case we also talked to risk management, we talked to ethics. Ethics I think actually met with the patient as well just so that we were very clear about—the patient knew that he had options. Again, the hospice piece was important—to know that there were other options through hospice. So um, **it just seemed that there was a whole lot involved that first time** and I thought if we have to do this every time. **Now we’ve got it down a little bit better.**” (Physician)

“I felt so bad that I had not started the process with him earlier. So, each one you do you learn, you learn something. I should have started that, I should have said to him you need to get up here, you need to get up here now when things are not bad. Have you been thinking about this, we need to get the drug early, we need to get the paperwork done. I waited until it was too late and then you couldn’t get through the second week.” (Physician)





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VIEWPOINT

Responding to Patients Requesting Physician-Assisted Death Physician Involvement at the Very End of Life

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Is physician-assisted death ever justifiable?—Yes.

Both the lived experience of a person with a serious illness as well as commonly recognized ethical principles provide guidance in answering this question. A woman in her 40s faced her ovarian cancer with great courage, sought available new oncologic treatments, and carefully researched how to relieve potential end-of-life pain, dyspnea, nausea, and other physical or psychosocial distress should it occur as she became sicker. She considered the possibility of physician-assisted death and received a prescription from her physician in Washington because it gave her "a way out" if her existence became intolerable. She was not certain she would use the medication, and she made sure her family supported her plan. In the end, with help from hospice, family, and clinicians, she felt the last part of her life was "surprisingly okay," and she died comfortably, in her home, the medications potentially intended to hasten death unused.

This case illustrates why physician-assisted death should be considered important enough to be made legally available. Patients with serious illness wish to have control over their own bodies, their own lives, and concern about future physical and psychosocial distress. Some view potential access to physician-assisted death as the best option to address these concerns. Appropriate safeguards, as enacted into law in Oregon, Washington, Vermont, Montana, and (recently) California, create a context in which individual physicians and their patients need not act in secrecy. Patients should be informed about palliative care options (including hospice), have access to expert symptom management, have a predictable time window between making the request and receiving the prescription, and have access to mental health services if needed. In Oregon, where physician-assisted death has been legal for 18 years, 1 in 6 terminally ill patients talks with their families, 1 in 50 talks with their physician, and only 1 in 500 directly accesses this option.¹ There are concerns about coercion, vulnerability, and slippery slopes—but these concerns have not been borne out by experience with legally open access to physician-assisted death in 4 states.²

Inquiries about physician-assisted death arise for clinicians in states where it is legal and illegal.^{3,4} Most common is a proactive planning inquiry, when a patient, faced with a serious illness, has concerns about future physical or psychosocial misery and asks about options. Physicians should respond by exploring patients' concerns and fears regardless of the legal status of physician-assisted death and their personal stance because many patient concerns can be addressed through careful at-

tention to symptom management, reassurance about commitment to address future problems, advance care planning, and hospice.

Requests to initiate physician-assisted death "right now" are much less common than inquiries, even in the states where the practice is legal.² Medical assessment should begin with an exploration of the underlying reasons the patient's situation has become unacceptable to understand the main concerns driving this request.^{3,4} Reassessing and focusing on palliative efforts to relieve distress are essential. Assessment of the patient's emotional state, especially whether the request is affected by depression, anxiety or delirium, is also required. An understanding of how the request is aligned with the patient's personal history and values provides additional perspective; family and friends (with the patient's permission) should be engaged to provide additional understanding and support. Representative questions for both of these inquiries are included in **Box 1**.

The involvement of physicians in care for a dying patient is a continuum (**Box 2**). Excellent symptom-directed care is a fundamental requirement and probably prolongs life more often than shortens it. However, for some scenarios, such as severe dyspnea in the last hours of life, aggressive symptom management must take the risk of (unintentionally) hastening death. Allowing natural death by forgoing or stopping life-extending therapy may also shorten survival, but wide societal ethical and legal consensus indicates such decisions are acceptable based on the patient's right to bodily integrity.⁵ Providing sedation near the end of life can address intractable symptoms although some physicians hesitate to administer it when the patient's distress is primarily psychosocial or in response to an explicit request to hasten death. Counseling patients about the possibility of voluntarily stopping eating and drinking is a practice for which limited data and published experience are available.⁵ Prescribing self-administered medication intended to hasten death is currently legal in 5 US states. Prescribing lethal medication administered by a clinician at the patient's request is legal in the Netherlands, Belgium, Luxemburg, Colombia, and Canada.

Uncomfortable emotional reactions, difficult discussions, and challenging self-reflection on personally acceptable and unacceptable practices are common for physicians exploring these options.⁶ It is nearly impossible for physicians or others to work closely with such patients without having some aspect of their personal values and boundaries touched. Conflicts and beliefs about the roles, relationships, faith, and control of physicians involved can be triggered, and clinicians must



Beyond patient requests

In July 2016, the VT Alliance for Ethical Healthcare and the Christian Medical and Dental Associations filed a federal lawsuit against the Board of Medical Practice and several other state agents.

Should physicians inform patients that they have the option of hastening death under Act 39 in Vermont?



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Providers' views on the duty to inform

8/19 providers reported waiting for patients to initiate

“I think because it’s new and people are sensitive, people pretty much ... across the board feel that **it needs to be a patient-directed question**. I don’t know of anybody who would put that on the table before somebody asked about it. ...For two reasons. Number one, the population that’s gonna ask about this ... they’re a savvy population. They’re people who really want control, they’re going to know about it; they’re going to ask. **And the people that aren’t going to ask may be less likely to be interested.** So that’s the way I think it.” (Physician)



Providers' views on the duty to inform

Nurse: We never bring it up. It's something that somebody else brings up with you.

MB: And is that an intentional choice?

Nurse : I think so, because my opinion is, I think you have to be careful about how people feel about this. And let's say, for example, that you have a relationship with the patient and the family, and it's a comforting, trusting relationship and they happen to be individuals who are completely against this. **If I bring that up and it's something that they wouldn't even consider, that could, create a huge scar in that relationship.** And so, again, they can bring it up and then you know that the door is open to that conversation, but, **unless that door was opened, I would not bring it up to a patient.**

Providers' views on the duty to inform

11/19 providers reported that there are circumstances in which they might initiate a discussion

“I try to bring it up ... [as] it's part of the slate of options, but I don't dwell on it. And a patient will pick up on it, if it's something they really want.” (Physician)

“I think I want my patients to understand everything that's available and I don't think it's fair to leave a patient in the dark. Whether or not they want to do it or ethically agree with it is not the issue. I want them to be informed.” (Physician)

“I think I brought it up maybe twice with patients, but mostly because, it would take very unusual situations.” (Physician)



Equal access to information?

Patients who already know about assisted dying are more likely to be more educated and from higher SES backgrounds.

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Privileging access for advantaged groups raises justice concerns (Buchbinder 2017, forthcoming)



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For further information

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